

**Second International PWS Caregivers Conference
Herne, Germany
July 6-8, 2009**

**Workgroup: Environmental Structure for PWS
Living - Best Practice Guidelines**

Chair: Hubert Soyer (Germany)

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Note: The reader is directed to the proceedings of the Herne I workgroup on **Environmental Structure of Living** for a review of presentations, group discussion, and standards of care. The Best Practice Guidelines derived during the Herne I conference were reviewed and refined during Herne II. The consensus of the two workgroup discussions from Herne II is presented here.

All guidelines should take into account the assessment of the individual to assure health and safety and to promote quality of life.

- 1. The individual's opinion should be taken into account when following these guidelines whenever possible.**
- 2. The preferred form of living arrangement is in a PWS-specific environment.** This allows for consistency in treatment and a sense of fairness to the individual. All attempts to create a family like environment including their own space regardless of group size is important for the person with PWS to have a sense of belonging as well as a place to disengage from group living whenever necessary. In addition it is also vital for the individual to have a choice of vocational opportunities, as enjoyment and fulfillment of one's own day is crucial for anyone to feel productive and an important member of their community.
- 3. Optimal success for the person with PWS will be based on the type of supports that are in place.** Those supports require an understanding of the unique needs associated with PWS. All areas of a person with PWS' day should have proper supervision to assist with those unique needs. There

needs to be a 24 hour type of supervision in place in either the form of direct caregiver support, alarms or security systems that alert caregiver or monitoring agency that the individual has either left the designated area(s) or that they are in need of assistance. A combination of the above may also be used.

4. **At times additional support may be needed due behavioral issues or need for assistance from another caregiver.** Each supportive environment, both home and vocational, should have a system in place that allows for quick response from another caregiver to assist in the need at hand.
5. **Routine and consistency is essential to the successful living for a person with PWS.** Inclusion of their ideas and preferences should be part of the planning of the structure of their regular routine. Meals should be managed and structured in a formal way to ensure that everyone knows the plan of how meals are to be planned, monitored, and served. It is necessary for every person with PWS to have a diet plan that can be followed by all. Exercise should also be a part of their daily routine including some levels of movement or fitness every day with the amount of time to be determined on individual basis. Healthy weight management is also an important part of monitoring the progress of supporting a person with PWS. Weights should be taken at a minimum of once per week based on history.
6. **Structure of the home for a person with PWS should have some form of house rules for living with others.** This allows for everyone to understand and remain consistent with those guidelines, expectations, and boundaries that are needed when in a group living environment. Another area is the complete security of food, money, and medication which should be locked and managed by caregivers.
7. **To assist in overall self esteem it is important for everyone to feel a part of their community.** Inclusion of those activities within the community should be individually assessed to determine environmental supports that may be needed. Understanding the person's own level of independence will assist in maintaining required needs for safety. Living in a community should include good neighbor relationships, it is important to create systems explaining about PWS.
8. **It is essential to have individual behavior management plans ranging from positive motivation to crisis management.** This once again allows for consistency and proper understanding of that specific individual's needs when that person may be in a crisis or to simply avoid or redirect the situation.
9. **Training of caregivers is key to the success of the individual with PWS.** Caregivers need a good understanding of the complexity of the needs of the

syndrome as well as the compassion that is needed when supporting a person with PWS.

10. **Maintaining healthy relationships once the person with PWS is outside their family's home is important for the person with PWS.** Contact and involvement with family and friends may need additional support and guidance from caregivers. That support may consist of teaching relationship building and in some incidences may require additional counseling. Human sexuality may also require support and education.
11. **A clear structure is required to develop and maintain a healthy and stable relationship between the parents, the individual, and the caregiver.** These communications are most effective if they are team-based and have pre-determined professional boundaries established.
12. **Due to the potential for life-threatening situations, it is imperative to create an environmental structure that allows access to comprehensive medical services.**
13. **To support self determination as it relates to environmental structures, choices should be offered to assist the person to individualize their room while promoting personal safety.**
14. **In order to provide effective support services there needs to be an established form of communication and information systems in place for everyone involved in the care and treatment of the individual.**

Conclusions:

Across cultural lines, all participants agreed that in order for an individual with PWS to succeed and live a healthy and productive quality of life that a basic level of support, conducive to promoting safety and personal growth, must be in place prior to providing care. It was determined that **environmental supports were non-negotiable**, including but not limited to;

- food security,
- daily schedules,
- personal growth and development plans,
- trained caregivers, and a
- continuum of care throughout their day.

It was also agreed upon, that it is imperative that as care providers, we continue to explore this cohesive collaboration of efforts through on-going education, training, and awareness.

QED

Testimony in opposition to HB 6350:
An Act Concerning the Budget for the Biennium ending June 30, 2015

Senator Harp, Representative Walker, and Members of the Appropriations Committee: My name is Debbie Poerio, and I am the President/CEO of Integrated Health Services, who has administered East Hartford's School Based Health Center Program for 20 years.

I am submitting written testimony in opposition to HB 6350, *An Act Concerning the Budget for the Biennium ending June 30, 2015*, and its impact on School Based Health Centers (SBHCs). In an effort to be succinct, I will identify my concerns with the proposed cuts below.

1. Reduction of ~\$500,000 EACH YEAR to the current baseline of operational funding for SBHCs.

- In December 2012, the Governor rescinded more than a \$500,000 from School Based Health Centers as part of his deficit reduction plan. The half-million dollars was taken from the \$1.3 million dollars that had just been allocated by the Legislature for the new/expanded sites. Since the entire allocation for new or expanded health centers has been proposed to be eliminated in the FY2014 and FY2015 budget proposal, the continued reduction is being taken from operational funding to existing school based health centers.
- Funding reductions decrease direct clinical services – less clinical staff time to assess and treat student health problems and provide preventive care to keep them healthy and in school.
- While we understand the shared sacrifice we all have to make during these difficult fiscal times, the plan to annualize the rescission paired with the proposed elimination of expanded SBHC funding in the Alliance Districts equals a 15% decrease to the total state funding for the program.

2. Elimination of funding for new or expanded SBHCs in the Educational Alliance Districts

- This contradicts the intent of the Governor's Education Reform Initiative, in which the Legislature allocated \$1.3 million dollars to fund 22 new or expanded School Based Health Centers in the Alliance Districts for FY 2012.
- FY 2012 Funding of this Initiative was just released through a Request for Proposal by the Department of Public Health which will be awarded by May, 2013, and would therefore result in creating 22 new/expanded SBHCs that would only be open from May-June 30, with no continuation of the funding if the Governor's reductions are allowed to stand for the FY 2013 budget. Surely the legislature did not intend to invest in opening new SBHCs only to close them within 6 weeks.

These reductions follow too closely on the heels of Sandy Hook, a time when the Governor and President have committed to the need to invest in the provision of mental health services to our children, and identifies that the best place to provide them is through the SBHCs. School Based Health Centers eliminate such barriers to care, particularly to mental health care, including location, cost, and the social stigma that prevents many children, adolescents, and families from accessing the care they need. SBHC providers are specialists who are trained to meet the unique needs of children and adolescents. The SBHC model that provides treatment in the school allows for more systematic detection, assessment, treatment, and essential care coordination that ensures our students are healthy, and ready to learn.

I urge you to not only to avoid these drastic reductions to School Based Health Center services, but to invest in the expansion and creation of new SBHCs. For so many children and families, the SBHC is the safety net that keeps children in school and parents at work.

Thank you.